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Published in:
Social Science and Medicine

DOI:
[10.1016/j.socscimed.2019.112660](https://doi.org/10.1016/j.socscimed.2019.112660)

Publication date:
2020

Document Version
Author accepted manuscript

[Link to publication in ResearchOnline](#)

Citation for published version (Harvard):

McHugh, N, Pinto-Prades, JL, Baker, R, Mason, H & Donaldson, C 2020, 'Exploring the relative value of end of life QALYs: are the comparators important?', *Social Science and Medicine*, vol. 245, 112660.
<https://doi.org/10.1016/j.socscimed.2019.112660>

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Title

Exploring the relative value of end of life QALYs: are the comparators important?

Authors

Neil McHugh¹, José Luis Pinto-Prades², Rachel Baker¹, Helen Mason¹ and Cam Donaldson¹

Affiliations

1. Yunus Centre for Social Business and Health, Glasgow Caledonian University
2. Department of Economics, University of Navarra, Pamplona, Spain

Corresponding Author

Neil McHugh
Yunus Centre for Social Business and Health
M201, 2nd Floor, George Moore Building,
Glasgow Caledonian University
Cowcaddens Road
Glasgow G4 OBA
neil.mchugh@gcu.ac.uk

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Abstract

In the UK, life extending, end-of-life (EoL) treatments are an exception to standard cost-per-quality-adjusted life year (QALY) thresholds. This implies that greater value is placed on gaining these QALYs, than QALYs gained by the majority of other patient groups treated for anything else in the health system, even for other EoL contexts (such as quality of life (QoL) improvements alone). This paper reports a Person Trade-Off (PTO) study to test whether studies that find societal support for prioritising EoL life extensions can be explained by the severity, in terms of prospective QALYs loss, of the non-terminal comparator scenarios.

Eight health scenarios were designed depicting i) QoL improvements for non-EoL *temporary* (T-QoL) and *chronic* (C-QoL) health problems and ii) QoL improvements and life extensions (LEs) for EoL health problems. Preferences were elicited from a quota sample of 901 Scottish respondents in 2016 using PTO techniques via Computer Assisted Personal Interview (CAPI).

Our results indicate that there is little evidence to suggest that the severity of non-EoL comparator scenarios influence preferences for EoL treatments. Respondents do not appear to have a preference for EoL over non-EoL health gains; instead there is some indication that non-EoL health gains are preferred, particularly when compared to EoL-LE health gains. Comparing between QoL and life extending EoL scenarios, our results suggest QoL improvements are preferred to life extensions. Overall, results challenge current UK EoL

policy which gives additional weight to EoL health gains, particularly EoL life extensions in the case of the National Institute for Health and Care Excellence (NICE).

Keywords

End-of-life; life extension; person trade-off; comparators; stated preferences; UK

1. Introduction

Health Technology Assessment (HTA) agencies typically consider the cost per quality-adjusted life year (QALY) of new technologies, compared to existing technologies, against a threshold. In the UK, this threshold is £20,000-£30,000 per QALY, above which treatments are unlikely to be recommended for provision (NICE, 2013). However, since the introduction of cost-per-QALY thresholds, there has been debate about whether a QALY is a QALY is a QALY (Baker et al., 2010; Donaldson et al., 1988). Some exceptions to the standard threshold now exist, for example, in 2009 the National Institute for Health and Care Excellence (NICE) introduced supplementary guidance that gave special consideration to life-extending, end-of-life (EoL) treatments (NICE, 2009). In England, a threshold of £50,000 per QALY has emerged for these treatments (Dillon & Landells, 2018). This implies that greater value is placed on gaining these QALYs, than QALYs gained by the majority of other patient groups treated for anything else in the health system, even for other EoL contexts (such as quality of life (QoL) improvement alone). The focus of this paper is whether studies that find societal support for prioritising EoL life extensions can be explained by a specific severity concern, prospective QALY loss, which may also apply to other groups and interventions. Given policy priority for such specific QALY gains, the key empirical question becomes whether this has been established through comparison with less-severe patient scenarios and, thus, the extent to which the severity of non-terminal comparator scenarios might explain relative societal values of life-extending EoL QALYs.

1.1. Background

1.1.1. Empirical evidence

Influencing the case for NICE's EoL policy was the claim that society places special value on these types of health gains (Rawlins et al., 2010). However, this claim was not based on evidence and a recent review of twenty-three empirical studies has found that evidence is equivocal; eight studies reported results suggesting a positive premium for EoL, eleven negative and four report mixed findings (Shah et al., 2018). While the majority of methods used could be categorised as either *choice* or *matching* a variety of approaches are utilised, for example: discrete choice experiments (DCEs) (Rowen et al., 2016; Shah et al., 2015; Skedgel et al., 2015), budget allocation (Linley & Hughes, 2013), person trade-off (PTO) (Pinto-Prades et al., 2014) and willingness to pay (WTP) (Pennington et al., 2015; Pinto-Prades et al., 2014; Shirowa et al., 2013). These approaches have different theoretical underpinnings (e.g. welfare economics (WTP) and consumer theory (DCEs)), use different framings (e.g. people (PTO) and pounds (WTP)) and are answered from different perspectives (e.g. individual (WTP) and social (PTO and budget allocation)). Despite the variation in methods and study design, in general, respondents express a value for EoL treatment scenarios and (a range of) non-EoL alternative treatment scenarios. Comparing these values allows examination of relative values. Thus the design of the alternative scenarios (the comparators) is crucial as respondents' relative values may depend on those alternatives. For example, the relative value of 'X' could be dependent on whether the comparator is 'Y' or 'Z' or something else. If 'X' is three months life extension for terminally ill patients, its value might be different when compared to a QoL gain for patients with a

temporary health condition in relatively good health ('Y') than a similar QoL health gain but to patients in very poor health ('Z'). Thus the severity of the non-EoL comparator scenario(s) might explain relative societal values of EoL QALYs. This is important as NICE EoL policy does not distinguish between different types of QALYs; life-extending, EoL QALYs are, in effect, more valued than the vast majority of other QALY types. So in considering the relative value of a QALY a necessary question is "... in comparison to what?"

1.1.2. The importance of comparators

Within studies that did not find an EoL premium, the non-EoL comparators used in Linley and Hughes (2013) and Shah et al. (2015) are the most severe in terms of prognosis. Linley and Hughes (2013) set-out a choice between providing a treatment that extends life by six months for a disease that leads to death in 18 months (EoL) or in 60 months (non-EoL) without treatment. Likewise, in the DCE of Shah et al. (2015), life expectancies without treatment for EoL scenarios are three months, one year or two years compared to only three or five years for non-EoL scenarios. An issue with these comparators is that life expectancies are so poor that respondents may have interpreted all scenarios as being EoL. Interestingly, in a DCE where the non-EoL life expectancies are larger (five, ten, thirty and sixty years), and consequently the 'comparator' situation is less severe, a positive EoL premium is found (Rowen et al., 2016).

The potential influence of less severe comparators on relative values is best illustrated in Shirowa et al. (2013), Pennington et al. (2015) and Pinto Prades et al. (2014). These three studies use *temporary* health problems in which current or normal health (100%) is returned

to following a period of illness; the size of the QALY health gains were also the same for EoL and non-EoL within each of these respective studies. While Pennington et al. (2015) and Pinto-Prades et al. (2014) find an EoL premium, Shiroyiwa et al. (2013) find mixed results. The non-EoL comparators in Shiroyiwa et al. (2013) feature mild, moderate and severe *temporary* health states; severity is defined in terms of QoL at the onset of illness. EoL-LE scenarios featured a life extension (LE) for a severe initial QoL health state and a life extension in perfect health for a life-threatening situation (an initial health state was not provided). Although average WTP per QALY values were higher for health gains for EoL health states than for mild *temporary* conditions, in general, treatments for moderate and severe *temporary* health states received higher average WTP per QALY values. These results suggest severity in terms of prospective QALY loss may not influence values as average WTP per QALY values were higher for non-EoL scenarios when the same onset QoL health state – severe – was used in both non-EoL and EoL scenarios. However, these relative values are *across* rather than *within* sample as respondents were only asked their WTP for one scenario. Also the EoL life expectancy untreated was only one month and treatment would have extended their life in a severe health state. This poor prognosis compared to treatment for non-EoL scenarios resulting in immediate recovery may also explain these findings.

In Pennington et al. (2015) non-EoL scenarios included a 25% QoL loss over four years; a 10% QoL loss over ten years; and time spent in a coma and in Pinto-Prades et al. (2014) the patient had 30% health for six or 18 months with an initial treatment. The EoL premium found in both studies could be because comparators are depicted as mild conditions in which patients will recover with no lasting effects, for example, after a period in a coma respondents' are told they will return to their current health and "pick up where you left

off” (Pennington et al., 2015, p284). Also neither study explored the effect of severity in terms of prospective QALY loss. Indeed, no EoL study has yet designed and introduced a *chronic* scenario in which the patient does not return to full health (or better health) following the treatment period but instead remains in a state of worse health, than at the point of diagnosis, for the foreseeable future. In terms of prospective QALY loss the EoL scenario would still be the most severe case but a severity gradient would be created whereby the order of severity is: EoL > chronic > temporary. This would enable examination of whether the severity of non-EoL comparator scenarios might explain relative societal values of such life-extending EoL QALYs.

Pinto-Prades et al. (2014) is also only one of a handful of studies to examine the relative value of health gains between EoL scenarios. This is important as NICE EoL policy does distinguish between types of EoL health gains; *only life extensions* are prioritised. This policy is contradicted by the limited available evidence as four of five studies indicate that quality of life improvements within EoL may be more preferred (Hansen and Kjær, 2019; McHugh et al., 2018; Pinto-Prades et al., 2014; Shah et al., 2014); only Shah et al. (2015) found a preference for life extensions. However, no study has yet examined preferences for different compositions of life extensions at the EoL i.e. a longer life extension in a lower QoL versus a shorter life extension in a higher QoL.

The aim of this study is to test how the severity of the non-EoL comparator scenario affects the relative value of EoL QALYs and to examine the relative value of different types of QALYs gained at the EoL. We do this by building on Pinto-Prades et al. (2014) through the introduction of new scenarios, eliciting preferences using the PTO approach. From a

normative standpoint this approach better reflects the questions under consideration as it is 'other focused' and takes a social decision maker perspective. In summary, this paper will focus on the following research questions which have different degrees of novelty:

1. Are preferences for EoL treatments contingent upon the severity of the non-EoL comparator? For EoL treatments that:
 - a. extend life (EoL-LE)
 - b. improve quality of life (EoL-QoL)

These questions have not been addressed formally in the literature.

2. Are preferences for EoL treatments contingent upon the type of health gain i.e. life extension versus quality of life?

There is very limited evidence about this issue (Hansen and Kjær, 2019; McHugh et al., 2018; Pinto-Prades et al., 2014; Shah et al., 2015; Shah et al., 2014).

In the next section we present a survey aimed at addressing these questions.

2. Methods

2.1. Scenarios

The survey was based on eight scenarios (see Table 1) designed to enable comparisons which respond to the above research questions. In all cases, participants had to choose between treatments that provide exactly the same health gain (0.5 QALYs) for different

health problems: terminal (EoL) conditions, a chronic (C) health problem and a temporary (T) health problem. Two of the eight scenarios in Table 1 can be considered as *benchmark* scenarios (S7-S8). These scenarios represent cases that NICE EoL Guidance gives special value to i.e. short life extensions to those with a terminal illness (EoL-LE). (Relatively) small health gains (0.5 QALYs) were used, which reflects the (upper end) of the QALY gains considered through the EoL policy. Different life expectancy and QoL combinations of the 0.5 QALY gain were also used in these two scenarios to allow for a new way to explore the relative value of health gains within EoL: a one-year life expectancy gain at 50% QoL (S7) and a seven months' life expectancy gain at 80% QoL (S8). In the other six comparator scenarios (S1-S6) the 0.5 QALY gain was achieved by improving QoL by 50% for a period of one year; QoL at the point of treatment was either 30% or 50% meaning QoL improved to either 80% or 100%. QoL was depicted on a scale from Dead to 100% (full health) and EQ-5D-5L (Herdman et al., 2011) descriptions were used to illustrate how the QoL percentages – 80%, 50% and 30% – in the scenarios could be described. Since all scenarios presented to participants were interpreted as better than death, in terms of prospective QALY loss, the terminal case is the most severe health problem and the chronic condition is more severe than the temporal one. Table 1 summarises all eight scenarios.

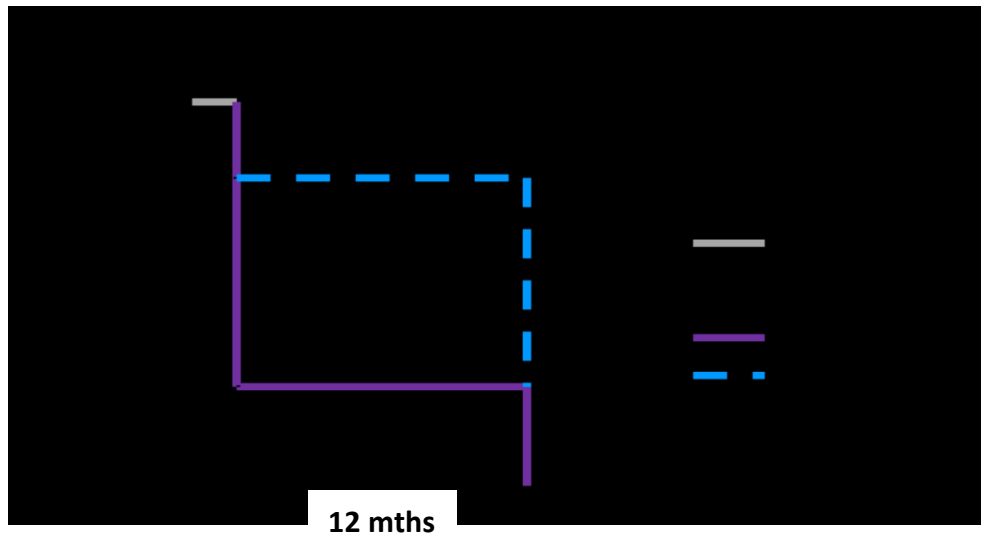
Table 1 – Scenario Descriptions

| Scenario Descriptions | | | | | | | | | |
|-----------------------|---------|----------------------|---------------------|---------------------|---------------|---------------------|-------------------|---|-------------------|
| Scenarios (S) | | QoL Prior to Illness | Current Treatment | | New treatment | | QoL After Illness | Health Gain from New Treatment (QoL / Length) | QALY Gain (QALYs) |
| No. | Type* | | QoL | Duration of illness | QoL | Duration of illness | | | |
| 1 | EoL-QoL | 100% | 30% | 1 year | 80% | 1 year | Death | 50% / 1 year | 0.5 |
| 2 | EoL-QoL | 100% | 50% | 1 year | 100% | 1 year | Death | 50% / 1 year | 0.5 |
| 3 | T-QoL | 100% | 30% | 1 year | 80% | 1 year | 100% | 50% / 1 year | 0.5 |
| 4 | C-QoL | 100% | 30% | 1 year | 80% | 1 year | 30% | 50% / 1 year | 0.5 |
| 5 | T-QoL | 100% | 50% | 1 year | 100% | 1 year | 100% | 50% / 1 year | 0.5 |
| 6 | C-QoL | 100% | 50% | 1 year | 100% | 1 year | 50% | 50% / 1 year | 0.5 |
| 7 | EoL-LE | 100% | Decreasing to death | A few weeks | 50% | 1 year | Death | 50% / 1 year | 0.5 |
| 8 | EoL-LE | 100% | Decreasing to death | A few weeks | 80% | 7 months | Death | 80% / 7 mths | 0.47 |

* Quality of life (QoL) and life extending (LE) improvements for end of life (EoL) health problems (EoL-QoL and EoL-LE). QoL improvements for Non-EoL *temporary* (T-QoL) and *chronic* (C-QoL) health problems.

Scenarios were presented diagrammatically (Figure 1). The vertical axis represents QoL and the horizontal axis shows time. Prognosis untreated is shown by the (solid) purple line and the blue dashed line shows the effect of treatment (i.e. health gain). Diagrams were explained to respondents by animating lines on the graph in turn with corresponding text (see Appendices 1-2).

Figure 1 – Scenario 1 (S1)



2.2. Elicitation procedure

PTO questions are typically used to elicit societal (or citizens') preferences (Nord, 1995). In our study respondents were asked to imagine a situation in which the NHS has a fixed, additional budget and two new treatments are available (A and B) each of which can treat 100 patients (see Appendix 2). Only one treatment can be chosen. Respondents took the role of societal decision maker and were asked which treatment should be provided (respondents were not a patient in this scenario). The number of patients in the most preferred group was then altered using a bi-section approach. For example, if A was preferred the next question was 50A vs. 100B this continued until a point of indifference was reached signifying equivalence between the two groups. This indicates the *relative value* placed on the two options.

2.3. *Structure of survey*

The survey (see Table 2) was split into 6 versions (V1A-3B). V1A-1B focused on EoL-LE vs. non-EoL health problems, V2A-2B focused on EoL-QoL vs. non EoL health problems and V3A-3B focused on different types of EoL health gains. Versions contain different framings of the same scenario, for example, S7 (V1A) and S8 (V1B) are both EoL-LE scenarios representing a 0.5 QALY gain but are comprised of different QoL and life extensions (see Table 1). Preferences were elicited using PTO, WTP and Benefit Trade-Off (BTO) techniques. This paper focuses on the analysis of PTO data only; findings from the other approaches will be reported separately. The questionnaire concluded with socio-demographic questions. Appendix 3 shows the script used in the introductory animation and Appendix 2 details the text of the PTO questions.

The structure of the survey is shown in Table 2. Respondents were presented with an information sheet about the study and given the opportunity to ask questions before providing informed consent. Initial socio-demographic questions were asked to assess if respondents met the quota criteria (see 'Piloting and Data Collection'). A short, animated video then introduced the context and premise of the study. The video describes, in simple terms, the issues of scarcity and opportunity cost within the NHS and the need to make decisions about the provision of treatments and services. It explains that many different things could be considered when making decisions about how best to allocate resources, such as severity of illness or quality of life or life extension, and that it is important to know the views of the general public (see Appendix 3 for the script). Block 1 concluded with an

explanation of the health scenarios explained using examples (see Figure 1). The order of Blocks 2-4 were randomised and the questions within these blocks were randomised. The survey finished with a number of socio-demographic questions (Block 5).

| Version (V) | 1A | 1B | 2A | 2B | 3A | 3B |
|-----------------------------------|---------------------------------------|--|--|--|---|--|
| Block 1 (Introduction) | Initial quota demographics | | | | | |
| | Introduction and Video | | | | | |
| | Health Diagram Explanation | | | | | |
| Block 2 (PTO) | A: EoL-LE vs. T-QoL (S7 vs. S3) | B: EoL-LE vs. T-QoL (S8 vs. S5) | E: EoL-QoL vs. T-QoL (S1 vs. S3) | F: EoL-QoL vs. T-QoL (S2 vs. S5) | K: EoL-LE vs. EoL-QoL (S7 vs. S1) | K: EoL-LE vs. EoL-QoL (S7 vs. S1) |
| | C: EoL-LE vs. C-QoL (S7 vs. S4) | D: EoL-LE vs. C-QoL | G: EoL-QoL vs. C-QoL (S1 vs. S4) | H: EoL-QoL vs. C-QoL (S2 vs. S6) | L: EoL-LE vs. EoL-LE (S7 vs. S8) | L: EoL-LE vs. EoL-LE (S7 vs. S8) |

Table 2 – Survey Design

| | | | | | | |
|-------------------------------------|--|--------------------------------------|--------------------------------------|--------------------------------------|--|--|
| | | (S8 vs. S6) | | | | |
| | I: T-QoL vs. C-QoL (S3 vs. S4) | J: T-QoL vs. C-QoL (S5 vs. S6) | I: T-QoL vs. C-QoL (S3 vs. S4) | J: T-QoL vs. C-QoL (S5 vs. S6) | | |
| Block 3 WTP | <i>WTP responses are not reported here</i> | | | | | |
| Block 4 BTO | <i>BTO responses are not reported here</i> | | | | | |
| Block 5 (Socio-Demographics) | Socio-Demographic Questions | | | | | |

2.4. Addressing the Research Questions (RQs)

Using this survey design, the RQs presented in the introduction were addressed as follows:

1. Are preferences for EoL treatments contingent upon the severity of the non-EoL comparator? For EoL treatments that:
 - a. extend life (EoL-LE)
 - b. improve quality of life (EoL-QoL)

These questions are responded to using the following comparisons from V1A-2B in Table 2:

- EoL-LE vs. T-QoL: PTOs A and B
- EoL-LE vs. C-QoL: PTOs C and D
- EoL-QoL vs. T-QoL: PTOs E and F
- EoL-QoL vs. C-QoL: PTOs G and H

Previous literature (see Pinto-Prades et al. (2014)) indicates that EoL-LE and EoL-QoL may be prioritised when compared to T-QoL given the severity of the terminal condition. However, preferences for EoL-LE could vanish or be attenuated when C-QoL is the comparator as this condition is more severe than T-QoL.

2. Are preferences for EoL treatments contingent upon the type of health gain i.e. life extension versus quality of life? This is responded to in two different ways:
 - a. Between-subject comparisons: V1A-2B responses to T-QoL and C-QoL, respectively, are compared to EoL-LE and EoL-QoL:
 - i. T-QoL vs. EoL-LE and EoL-QoL: PTOs A and E; and PTOs B and F
 - ii. C-QoL vs. EoL-LE and EoL-QoL: PTOs C and G; and PTOs D and H
 - b. Within-subject comparisons: using V3A-3B the following comparisons are made:
 - i. EoL-LE vs. EoL-QoL: PTO K
 - ii. EoL-LE vs. EoL-LE: PTO L

In V3A-3B there are two different framings of EoL-LE: in S7 a 0.5 QALY gain is achieved with a smaller gain in QoL (50%) and a larger life expectancy gain (one year) than in S8 (80% QoL

gain for seven months' life expectancy gain). This comparison is new in the literature and provides a different way to examine preferences for health gains within EoL.

2.5. Piloting and Data Collection

The survey was programmed and administered by Accent (<http://www.accent-mr.com/>) and delivered via Computer Assisted Personal Interview (CAPI) by trained interviewers.

Prior to programming, survey questions were piloted via in-depth, one-on-one, interviews by the project team with members of the Scottish general public (n=60) to test the interpretation and design of the scenarios. In addition, further face-to-face piloting with a convenience sample of university colleagues focused on the design and wording of survey questions on the CAPI device. Minor modifications were made to the presentation, and the total number of questions asked in each version was altered to enable completion of the survey, on average, in less than 30 minutes.

Respondents were quota sampled across Scotland on basis of age, gender, employment status and location (rural/urban). Questions were administered in respondents' homes and a £5 voucher was offered as an incentive.

2.6. Data Analysis

In general, data analysis focuses on individual PTO pairings within each version of the survey. Only data across different versions of the survey which correspond to the same

scenario pairing were pooled and analysed together. For example, PTO I: S3 vs. S4 (T-QoL vs. C-QoL) data were pooled from V1A and V2A.

2.6.1. PTO data

Respondents' relative preference between patient groups are indicated through calculation of PTO ratios – 'median of ratios' and the 'ratio of means' (see Appendix 4 for details and illustrative calculations). While there is no single, correct approach for aggregating PTO ratios, there is consensus that – calculating the 'mean of ratios' – should be avoided as this ratio is affected by outliers (Baker et al., 2010; Chilton et al., 2002; Pinto-Prades et al., 2014). A PTO ratio of 1 indicates that respondents are indifferent between the two treatments and a ratio >1 indicates that *more* patients need to receive the *less* preferred treatment to produce the same benefit as 1 patient receiving the *more* preferred treatment. Strength of preference is examined in two additional ways. The average point of indifference for participants who prefer treatment X is compared to the average point of indifference for participants who prefer treatment Y i.e. $No.X(\text{mean})=100Y$ vs. $100X=No.Y(\text{mean})$; the lower the mean point of indifference, the stronger the strength of preference. 'Extreme' preferences are defined as responses where 1 patient receiving the most preferred treatment is valued as equivalent to 100 patients receiving the least preferred treatment. Additionally, 95% confidence intervals (CI) and chi-square tests are calculated for respondents' initial binary choice between A and B.

2.7. Research Ethics

Ethical approval for this study was obtained from the Glasgow School for Business and Society Research Ethics Committee, Glasgow Caledonian University (reference GSBS EC 05).

3. Results

3.1. Sample

Data were collected in two waves: May to June 2016 and September to October 2016 (the research team deemed time stamps of 206 surveys in the first wave as too short (completed in <13 minutes) so new data was collected (the second wave)). In total 901 respondents completed the survey, nationally representative of Scotland with respect to age, gender, employment status and location; versions were broadly comparable (see Table 3).

Table 3 – Socio-demographic characteristics: versions and total sample

| Variables | Version | | | | | | | | | | | | Total | | Scotland^ |
|-------------------------------------|---------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-------|-----|-----------|
| | 1A | | 1B | | 2A | | 2B | | 3A | | 3B | | | | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | % |
| Gender | | | | | | | | | | | | | | | |
| Male | 79 | 54% | 55 | 37% | 67 | 45% | 84 | 53% | 65 | 45% | 84 | 56% | 434 | 48% | 48% |
| Female | 68 | 46% | 95 | 63% | 82 | 55% | 76 | 48% | 80 | 55% | 66 | 44% | 467 | 52% | 52% |
| Age | | | | | | | | | | | | | | | |
| 18-30 | 26 | 18% | 26 | 17% | 31 | 21% | 41 | 26% | 32 | 22% | 32 | 21% | 188 | 21% | 21% |
| 31-50 | 51 | 35% | 54 | 36% | 55 | 37% | 56 | 35% | 51 | 35% | 52 | 35% | 319 | 35% | 35% |
| 51-64 | 39 | 27% | 35 | 23% | 33 | 22% | 35 | 22% | 26 | 18% | 39 | 26% | 207 | 23% | 23% |
| 65-74 | 17 | 12% | 19 | 13% | 12 | 8% | 18 | 11% | 21 | 14% | 18 | 12% | 105 | 12% | 21% |
| 75+ | 14 | 10% | 16 | 11% | 18 | 12% | 10 | 6% | 15 | 10% | 9 | 6% | 82 | 9% | |
| Area | | | | | | | | | | | | | | | |
| Urban | 119 | 81% | 115 | 77% | 127 | 85% | 138 | 86% | 114 | 79% | 127 | 85% | 740 | 82% | 82% |
| Rural | 28 | 19% | 35 | 23% | 22 | 15% | 22 | 14% | 31 | 21% | 23 | 15% | 161 | 18% | 18% |
| Employment | | | | | | | | | | | | | | | |
| Employed | 81 | 55% | 70 | 47% | 90 | 60% | 104 | 65% | 79 | 54% | 100 | 67% | 524 | 58% | 60% |
| Unwaged | 30 | 20% | 41 | 27% | 24 | 16% | 32 | 20% | 28 | 19% | 21 | 14% | 176 | 20% | 20% |
| Retired | 36 | 24% | 39 | 26% | 35 | 23% | 24 | 15% | 37 | 26% | 29 | 19% | 200 | 22% | 20% |
| Household income | | | | | | | | | | | | | | | |
| Low (less than £20,800) | 58 | 39% | 70 | 47% | 72 | 48% | 60 | 38% | 62 | 43% | 52 | 35% | 374 | 42% | 37% |
| Middle (£20,800 - £51,999) | 37 | 25% | 46 | 31% | 38 | 26% | 56 | 35% | 42 | 29% | 56 | 37% | 275 | 31% | 42% |
| High (more than £51,999) | 32 | 22% | 13 | 9% | 9 | 6% | 17 | 11% | 11 | 8% | 12 | 8% | 94 | 10% | 20% |
| Education | | | | | | | | | | | | | | | |
| Low (up to GCSE) | 38 | 26% | 69 | 46% | 55 | 37% | 46 | 29% | 51 | 35% | 42 | 28% | 301 | 33% | 50% |
| Midde (Highers & Further Education) | 75 | 51% | 56 | 38% | 79 | 54% | 87 | 54% | 67 | 47% | 75 | 50% | 439 | 49% | 24% |

| | | | | | | | | | | | | | | | |
|--|------------|-----|------------|-----|------------|-----|------------|-----|------------|-----|------------|-----|------------|------------|------------|
| High (University) | 32 | 22% | 23 | 15% | 13 | 9% | 25 | 16% | 22 | 15% | 26 | 17% | 141 | 16% | 26% |
| Marital Status | | | | | | | | | | | | | | | |
| Single/Never married | 49 | 33% | 52 | 35% | 42 | 28% | 44 | 28% | 41 | 28% | 41 | 27% | 269 | 30% | 28% |
| Married/ Living with partner/ Civil partnership | 71 | 48% | 62 | 41% | 71 | 48% | 84 | 53% | 65 | 45% | 78 | 52% | 431 | 48% | 42% |
| Divorced/Separated | 12 | 8% | 20 | 13% | 20 | 13% | 17 | 11% | 21 | 14% | 19 | 13% | 109 | 12% | 17% |
| Widowed | 14 | 10% | 15 | 10% | 15 | 10% | 15 | 9% | 18 | 12% | 10 | 7% | 87 | 10% | 13% |
| Ethnicity | | | | | | | | | | | | | | | |
| White | 140 | 95% | 147 | 98% | 144 | 97% | 157 | 98% | 141 | 97% | 146 | 97% | 875 | 97% | 96% |
| BME/other | 7 | 5% | 2 | 1% | 3 | 2% | 3 | 2% | 2 | 1% | 4 | 3% | 21 | 2% | 4% |
| Religion | | | | | | | | | | | | | | | |
| Catholic | 17 | 12% | 28 | 19% | 40 | 27% | 29 | 18% | 25 | 17% | 29 | 19% | 168 | 19% | 17% |
| Church of Scotland | 42 | 29% | 39 | 26% | 35 | 23% | 44 | 28% | 47 | 32% | 41 | 27% | 248 | 28% | 34% |
| Other Christian | 19 | 13% | 22 | 15% | 9 | 6% | 6 | 4% | 7 | 5% | 7 | 5% | 70 | 8% | 6% |
| Other religions | 10 | 7% | 1 | 1% | 2 | 1% | 2 | 1% | 2 | 1% | 4 | 3% | 21 | 2% | 3% |
| No religion | 57 | 39% | 51 | 34% | 57 | 38% | 71 | 44% | 60 | 41% | 64 | 43% | 360 | 40% | 39% |
| n | 147 | | 150 | | 149 | | 160 | | 145 | | 150 | | 901 | | |

Note. NB: For some questions there was an option to answer “do not know”, “prefer not to say” or “other”, these responses are not included in the table and may affect the numbers adding up to the total sample. ^Figures are based on Scotland’s Census (2011), except household income which is based on UK wide data (ONS, 2014).

Table 4 – PTO Results: preferences for EoL vs. non-EoL health gains

| PTO | A | B | C | D | E | F | G | H |
|---|--|---|--|---|---|---|---|---|
| Version | 1A | 1B | 1A | 1B | 2A | 2B | 2A | 2B |
| Scenario Type (X vs Y) | EoL-LE vs. T-QoL | | EoL-LE vs. C-QoL | | EoL-QoL vs. T-QoL | | EoL-QoL vs. C-QoL | |
| X (Scenario) vs. Y (Scenario) | 50%/1yr (S7) vs. 30-80%/1yr (S3) | 80%/7mths (S8) vs. 50-100%/1yr (S5) | 50%/1yr (S7) vs. 30-80%/1yr (S4) | 80%/7mths (S8) vs. 50-100%/1yr (S6) | 30-80%/1yr (S1) vs. 30-80%/1yr (S3) | 50-100%/1yr (S2) vs. 50-100%/1yr (S5) | 30-80%/1yr (S1) vs. 30-80%/1yr (S4) | 50-100%/1yr (S2) vs. 50-100%/1yr (S6) |
| 100X>100Y (95% CI) | 38%*** (30-46%) | 30%*** (23-37%) | 47% (39-55%) | 32%*** (25-39%) | 49% (41-57%) | 44% (36-51%) | 50% (42-58%) | 39%*** (32-47%) |
| No.X (Mean) = 100Y | 30 | 27 | 37 | 38 | 23 | 20 | 38 | 27 |
| Extreme preferences: 1X = 100Y⁺ | 25% | 42% | 23% | 33% | 38% | 44% | 23% | 38% |
| 100X<100Y (95% CI) | 62%*** (54-70%) | 70%*** (63-77%) | 53% (45-61%) | 68%*** (61-75%) | 51% (43-59%) | 56% (49-64%) | 50% (42-58%) | 61%*** (53-68%) |
| 100X=No.Y (Mean) | 18 | 19 | 27 | 21 | 19 | 15 | 25 | 21 |
| Extreme preferences: 1Y = 100X⁺ | 58% | 53% | 51% | 42% | 59% | 62% | 55% | 54% |
| Median of ratios (X:Y)[^] | 2.11 | 5.08 | 1.03 | 2.35 | 1 | 1.82 | 1 | 2.11 |
| Ratio of Means (X:Y)[^] | 1.48 | 1.81 | 1.15 | 1.73 | 1.06 | 1.25 | 1.10 | 1.37 |
| Total | 147 | 150 | 147 | 150 | 149 | 160 | 149 | 160 |

⁺These percentages show the proportion of respondents with extreme preferences among those who favoured Treatment X or Treatment Y. [^]These ratios represent the number of patients that have to receive Treatment X to produce the same benefit as one patient receiving Treatment Y. ***1% significance level; **5% significance level; *10% significance level.

Table 5 - PTO Results: preferences within non-EoL and within EoL health gains

| PTO | I | J | K | L |
|---|---|---|--|---------------------------------------|
| Version | 1A-2A | 1B-2B | 3A-3B | 3A-3B |
| Scenario Type X vs Y | C-QoL vs. T-QoL | | EoL-LE vs. EoL-QoL | EoL-LE vs. EoL-LE |
| X (Scenario) vs. Y (Scenario) | 30-80%/1yr (S4) vs. 30-80%/1yr (S3) | 50-100%/1yr (S6) vs. 50-100%/1yr (S5) | 50%/1yr (S7) vs. 30-80%/1yr (S1) | 50%/1yr (S7) vs. 80%/7mths (S8) |
| 100X>100Y (95% CI) | 44%** (38-50%) | 40%*** (35-46%) | 32%*** (27-37%) | 46% (40-51%) |
| No. X (Mean)=100Y | 32 | 28 | 33 | 42 |
| Extreme preferences: 1X = 100Y⁺ | 27% | 36% | 40% | 34% |
| 100X<100Y (95% CI) | 56%** (50-62%) | 60%*** (54-65%) | 68%*** (63-73%) | 54% (49-60%) |
| 100X=No.Y (Mean) | 21 | 25 | 35 | 36 |
| Extreme preferences: 1Y = 100X⁺ | 52% | 43% | 37% | 33% |
| Median of ratios (X:Y)[^] | 1.6 | 1.9 | 1.6 | 1.14 |
| Ratio of Means (X:Y)[^] | 1.26 | 1.28 | 1.41 | 1.12 |
| Total | 296 | 310 | 295 | 295 |

⁺These percentages show the proportion of respondents with extreme preferences among those who favoured Treatment X or Treatment Y. [^]These ratios represent the number of patients that have to receive Treatment X to produce the same benefit as one patient receiving Treatment Y. ***1% significance level; **5% significance level; *10% significance level.

3.2 Are preferences for EoL treatments contingent upon the severity of the non-EoL comparator?

Overall, there is little evidence that the severity of non-EoL comparator scenarios influence preferences (see Tables 4 and 5). These results indicate that respondents do not have a preference for EoL over Non-EoL health gains (see PTOs A-H). Instead Non-EoL health gains are preferred in the majority of cases; the results of PTOs A, B, D and H are statistically significant (see Table 4). This is in contrast to what is expected according to severity based on prospective QALY loss: aggregating across PTOs (A-H), approximately 59% of respondents

prefer non-EoL treatments to EoL-LE treatments. Across PTOs A-D, within-subject comparisons indicate that the severity of the comparators does not influence preferences for EoL-LE treatments. For example, comparing PTOs A and C suggests respondents have a higher preference for T-QoL than C-QoL when the comparator in both cases is EoL-LE (S7); support for EoL-LE decreases by 9% when T-QoL is the comparator and this finding is statistically significant. In relation to preferences for EoL-QoL (PTOs E-G), a within-subject comparison indicates severity may play a role. 61% of respondents (a statistically significant finding) prefer C-QoL in PTO H compared to 56% of respondents (not statistically significant) who prefer T-QoL in PTO F when the comparator in both pairings is EoL-QoL (S2). However, this finding is not replicated across PTOs E and G. In a direct comparison of non-EoL treatments (see Table 5, PTOs I and J), T-QoL is preferred to C-QoL which also goes against our predictions based on prospective QALY loss; these results are statistically significant.

3.2.1 EoL-LE vs non-EoL health gains

Our results suggest that non-EoL health gains are preferred to EoL-LE (see Table 4, PTOs A-D). More than 60% of respondents prefer non-EoL health gains in PTOs A, B and D (these results are statistically significant) and median of ratios are >2 indicating at least double the amount of patients need to receive an EoL treatment to produce the same benefit as 1 patient receiving a non-EoL treatment. For these same PTOs, ratio of means are not as pronounced but they are still >1 in favour of non-EoL health gains. PTO C also indicates a marginal preference for C-QoL (53%), although this result is not statistically significant and ratios are approaching 1. Across PTOs A-D, those preferring T-QoL and C-QoL have more extreme and stronger preferences. Approximately 51% of those preferring a non-EoL

treatment have extreme preferences compared to about 30% of those who prefer an EoL treatment (PTOs A-D). Also the average point of indifference for participants who prefer a non-EoL treatment ($100X = No.Y(\text{mean})$) is lower than the equivalent for those who prefer a EoL-LE treatment ($No.X(\text{mean}) = 100Y$), indicating participants who prefer non-EoL treatments have stronger preferences. For example, in PTO A 30 patients receiving EoL-LE (S7) produce the same benefit as 100 patients receiving T-QoL (S3), while 18 patients receiving T-QoL (S3) produce the same benefit as 100 patients receiving EoL-LE (S7); this suggests those who prefer T-QoL have stronger preferences.

3.2.2 EoL-QoL vs Non-EoL health gains

Results from PTOs E-H (see Table 4) suggest that EoL-QoL health gains are not preferred to non-EoL health gains and that EoL-QoL health gains are more preferred when patients' initial QoL is lower. Approximately 50% of respondents prefer EoL-QoL compared to T-QoL or C-QoL when the QoL health gain is from 30%-80% in all scenarios (see PTOs E and G). While a smaller proportion of respondents (approximately 42%) prefer EoL-QoL compared to T-QoL or C-QoL when the QoL health gain is from 50%-100% in all scenarios (see PTOs F and H); however, this finding is only statistically significant in PTO H. Median of ratios are equivalent (1) when initial QoL is 30%, while they are around 2, indicating a preference for non-EoL treatments, when initial QoL is 50%. Ratio of means are not as pronounced but they are still higher when initial QoL is 50%. Those respondents preferring T-QoL or C-QoL have stronger and more extreme preferences; initial QoL does not seem to affect these results.

3.3 Are preferences for EoL treatments contingent upon the type of health gain i.e. life expectancy versus quality of life?

Overall, our results suggest that QoL improvements are preferred to life extensions (see Tables 4 and 5). Between-subject PTO comparisons (see PTOs A-H) show a lower percentage of respondents prefer EoL-LE treatments when compared to non-EoL treatments (T-QoL and C-QoL) than when EoL-QoL treatments are compared to the same non-EoL treatments. For example, when the comparator in each PTO is T-QoL (S3) 38% of respondents prefer EoL-LE (S7) in PTO A compared to 49% of respondents who prefer EoL-QoL (S1) in PTO E. Ratios are generally closer to 1 when EoL-QoL scenarios are compared to non-EoL scenarios (PTOs E-H) than when EoL-LE scenarios are the comparator (PTOs A-D).

Within-subject PTO comparisons indicate that when choosing between different EoL health gains respondents may prefer options that result in greater QoL improvements (see Table 5, PTO K and L). 68% of respondents prefer EoL-QoL when compared to EoL-LE (PTO K), this result is statistically significant. While the results of PTO L are not statistically significant, 54% of respondents prefer the treatment providing a larger QoL health gain and shorter life extension (S8) compared to the smaller QoL health gain and longer life extension (S7). Although strength of preferences and extreme preferences are broadly equivalent for these two pairings, median of ratios and ratio of means indicate >1 patients have to receive life extending health gains (S7) to produce the same benefit as one patient receiving EoL-QoL (S1) or EoL-LE (S8).

4. Discussion

Overall, the results of this study provide little evidence to suggest that the severity of the non-EoL comparator scenario plays a role in the value assigned to EoL treatments. Respondents do not appear to have a preference for EoL over non-EoL health gains; and there is some indication that non-EoL health gains are preferred, particularly when compared to EoL-LE health gains. Within EoL scenarios, our results suggest that QoL improvements are preferred to life extensions.

The results of our study have similarities and differences with Pinto-Prades et al. (2014), on which this study builds that warrant discussion. Our study and Pinto-Prades et al. (2014) used similar scenarios to examine preferences for EoL-LE vs. T-QoL (PTO A), EoL-QoL vs. T-QoL (PTO E) and EoL-LE vs. EoL-QoL (PTO K). Regarding EoL vs. T-QoL health gains (PTO A and E), Pinto-Prades et al.'s (2014) findings indicate a preference for EoL health gains while our results suggest T-QoL is preferred when the comparator is EoL-LE and preferences for EoL-QoL and T-QoL are broadly equivalent. Both studies find that QoL health gains are preferred to life extending health gains at the EoL (PTO K). The difference in the value of EoL health gains when compared to T-QoL could be due to the different locations in which the studies were undertaken – Spain and Scotland – or, more likely, related to issues within the design of our scenarios. While our scenarios were broadly similar to those used in Pinto-Prades et al. (2014) they differed in relation to the description of the initial health states. As shown in Figure 1, our scenarios are presented in terms of *current* treatment and a potential *new* treatment meaning that even if the new treatment is not funded patients will receive the *current* treatment. Whereas, in Pinto-Prades et al. (2014) only those with a *temporary*

condition receive an initial treatment, equivalent to our *current* treatment; the EoL scenarios are initially presented *without* treatment. Thus it is possible that EoL health gains are preferred in Pinto-Prades et al. (2014) due to participants feeling the need to provide some treatment at the EoL whereas this rationale is not as strong in our study as all patients will receive an initial treatment. Further support for differences in access to treatment affecting preferences is provided by a recent study by Hansen and Kjær (2019). This study also uses scenarios based on Pinto-Prades et al. (2014) but as with our study, scenarios are presented in terms of *current* treatment and a potential *new* treatment and their results suggest a preference for health gains for *temporary* conditions over EoL health gains.

While Pinto-Prades et al. (2014) found a preference for EoL health gains, there is also evidence of preference heterogeneity; one group who strongly value EoL health gains, particularly short life extensions, and another group who place no or little value on these health gains. In our study there is also evidence of different groups with distinct views and within the wider literature, evidence is accumulating around plurality in preferences and views in relation to EoL (Hansen and Kjær, 2019; Mason et al., 2018; McHugh et al., 2015; McHugh et al., 2018; Pennington et al., 2015; Shah et al., 2015). Importantly, the results of this study and Pinto-Prades et al. (2014) suggest that a substantial proportion of respondents have lexicographic preferences, namely, that the treatment they prefer (EoL or non-EoL), should be given absolute priority in relation to the comparator. In our study this is indicated by respondents not making trade-offs e.g. stating 1 non-EoL=100 EoL and vice versa, approximately 42% of the PTO questions were answered in this way. The reasons for these views are not clear, as the CAPI survey did not incorporate qualitative work, after the pilot phase. However, in-depth work on societal views around EoL by McHugh et al. (2015)

suggests EoL treatments may not be valued by some if the health gain is not viewed as substantial while others will view (even short) health gains at the EoL as important if they help patients to prepare for a good death. These lexicographic preferences raise interesting methodological and policy questions. Stated preference approaches ask respondents to make trade-offs and then data is aggregated, typically, using the mean. While aggregation of PTO data uses median of ratios and ratio of means, it is not clear to what extent it is theoretically correct to aggregate preferences that are lexicographic, as indicated by respondents' refusal to make trade-offs. Relatedly, such preferences present a challenge for policymakers as they indicate that members of the public have entrenched points of view and are not willing to compromise. This makes the possibility of finding common ground unlikely and raises the probability of one societal group finding that their views are not represented in policy. This does provide an interesting avenue for future research around what should be done when people hold strongly, opposing views.

We extended Pinto Prades et al. (2014) by including new chronic scenarios (C-QoL) to examine whether the severity, in terms of prospective QALY loss, of the non-EoL comparator scenario affects the relative value of EoL QALYs. While our results provided little evidence that the severity of the non-EoL scenarios influences preferences, what was unexpected was the value respondents assigned to T-QoL health gains, particularly as the literature suggests the most severely ill tend to be prioritised (Gu et al., 2015; Nord & Johansen, 2014; Shah, 2009; Whitty et al., 2014). T-QoL may have found support as it enables patients to avoid most (S3) or the full effects (S5) of their illness and so lead (relatively) normal lives. While C-QoL may not have found as much support as expected if respondents saw little value in only temporarily postponing the effects of an illness that will

occur anyway. We know from piloting that respondents used both explanations but also that the T-QoL scenario was viewed as patients recovering anyway and so was not as valued. Unfortunately, the design of the main survey meant qualitative data was not collected alongside preferences with results suggesting respondents viewed T-QoL in a more favourable light.

We also built on Pinto-Prades et al. (2014) by replicating the same comparisons using different scenarios. For example, QoL health gains in EoL-QoL, T-QoL and C-QoL were from 30% to 80% and from 50% to 100%, whereas in Pinto-Prades et al. (2014) only a QoL health gain of 30% to 80% was utilised. When our comparisons were between EoL-QoL and non-EoL treatments more support was found for EoL-QoL when initial QoL was 30% as opposed to 50%. This could suggest that EoL-QoL treatments receive more support when viewed as a way to provide patients with a good death if terminally ill patients initial QoL is considered to be low. However, our survey design only enabled between-subject comparisons as opposed to within subject-comparisons and our design did not enable us to make similar comparisons for EoL-LE vs. non-EoL health gains. Future work examining whether there is a threshold, in terms of initial QoL, at which respondents switch their preferences would help us to better understand respondents' preferences for EoL health gains.

The results of this study add to a growing subset of studies, including Pinto-Prades et al. (2014), which question whether life extensions are preferred to QoL improvements at the EoL (Hansen and Kjær, 2019; McHugh et al., 2018; Shah et al., 2014). So far only Shah et al. (2015) have found that life extensions are preferred. Although the evidence base remains equivocal as to whether EoL health gains are preferred to non-EoL health gains, the results

of this study and others challenges current EoL policy by NICE and the Scottish Medicine Consortium (SMC) which give additional weight to EoL health gains. While SMC will consider QoL improvements, as well as other benefits, in their evaluation of EoL medicines that do not meet standard cost-effectiveness thresholds (SMC, 2016), it is unclear why NICE's EoL policy only gives additional weight to life extending health gains.

4.1. Limitations

This study has a number of limitations. Firstly, data collected via CAPI devices on a relatively large sample precluded the generation of qualitative data. This meant we were unable to explore how scenarios, including QoL percentages, were interpreted (beyond the initial pilot work) or the reasons for respondents' preferences. Secondly, a large proportion of respondents appear to have extreme preferences as they refuse to make trade-offs. This could indicate that respondents either did not understand the task or that the task poorly captured their preferences. While some kind of misunderstanding may have contributed to this result we do not believe that extreme preferences are an artefact of the method. As noted previously, other EoL studies have found evidence of extreme preferences; importantly, this is not restricted to PTO studies as similar results have also been observed in WTP studies (Pinto-Prades et al., 2014; Pennington et al., 2015). Moreover, there is evidence of extreme preferences in other, non-EoL, PTO studies. For example, in Pinto-Prades and Lopez-Nicolás (1998), respondents only had extreme preferences when the two outcomes seemed to be very different: saving 10 children's lives vs. relieving mild health problems of a larger number of people. One way to understand the extreme preferences found in EoL studies and in Pinto-Prades and Lopez-Nicolás (1998) is that when people are

very emotional about one issue whether that is children's lives or people with a terminal illness System 1 thinking (from dual process theory) takes priority (Stanovich & West, 2000). Kahneman (2011) describes that when this happens respondents are more likely to *substitute* an easier heuristic question for the target question and to make a *basic assessment*. Thus respondents who feel an emotional response to EoL questions may choose not to make a trade-off as they either view providing a short life extension in bad health as absurd or believe that everything possible should be done for those with a terminal condition. Future research which explicitly tests this hypothesis would help to enhance our understanding of EoL preferences. Lastly, our respondents were quota sampled across Scotland rather than the UK. While it is possible that English, Welsh or Northern Irish respondents could have different EoL preferences to Scottish respondents, the EoL Q2S (Q methodology-based survey design) study which investigated societal perspectives across the UK gave no indication that there were between country differences (Mason et al., 2018).

5. Conclusion

This study has cast doubt on whether the comparator's severity in terms of prospective QALY loss helps to explain the mixed findings in the EoL literature. Importantly for policy, our results suggest that when thinking as a social decision maker there is no clear preference for EoL (particularly life extending) health gains which raises questions regarding the policies currently used by NICE and to some extent SMC. Future work would benefit from more in-depth exploration of preferences that includes a significant qualitative component with a smaller sample of respondents to explore whether there is a threshold, in

terms of initial QoL, at which respondents' switch their preferences and the rationales given for the choice of treatments.

6. Acknowledgements

This work was funded by the Chief Scientist Office (CSO) Scotland (project reference number CZH/4/1055). We wish to thank Dr. Rohan Deogaonkar for help during the piloting phase of this work and the anonymous reviewers for comments that have helped to improve the paper.

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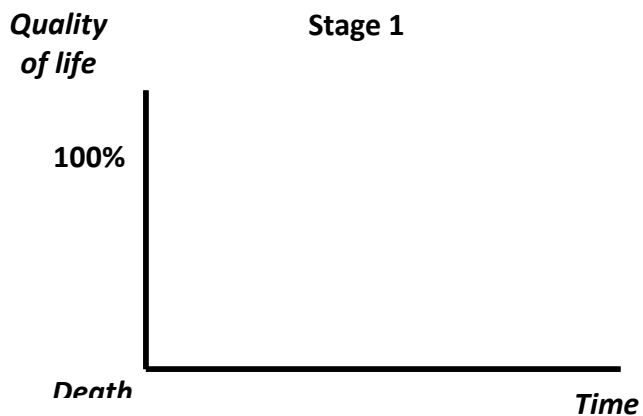
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Appendix 1: Health Scenario Diagrams

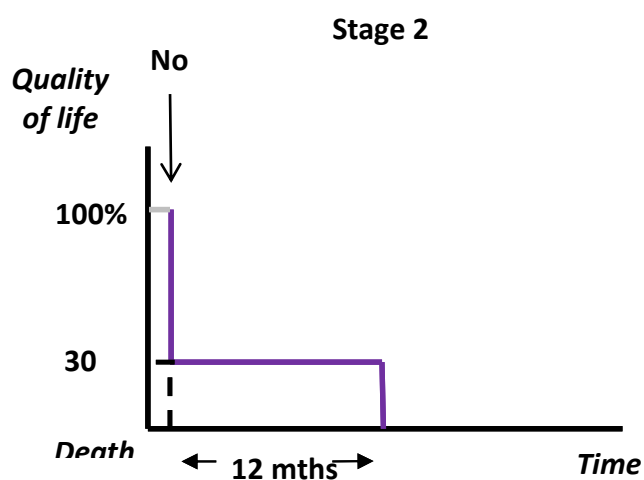
Notes on Appendix 1

- The same scale is used for quality of life percentages (vertical axis) throughout all diagrams. The axis for quality of life on the programmed version stops at 100%
- The same scale is used for life expectancy (horizontal axis) throughout.
- The area marked **HG** is always the same size. While dimensions differ for S8 (80% for 7 months) compared to the other scenarios (50% for 12 months) the size is broadly equivalent.
- A version of the text underneath each health scenario is used in our WTP and PTO questions.

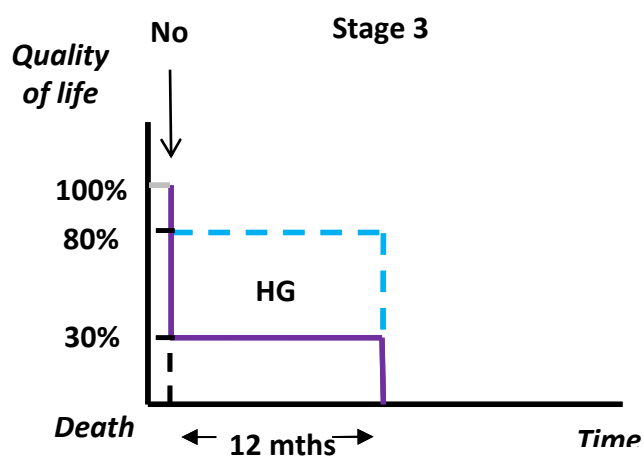
The following health scenario diagrams are constructed through the same three stages. For example:



Vertical line = quality of life (%)
Horizontal line = life expectancy (years & months)

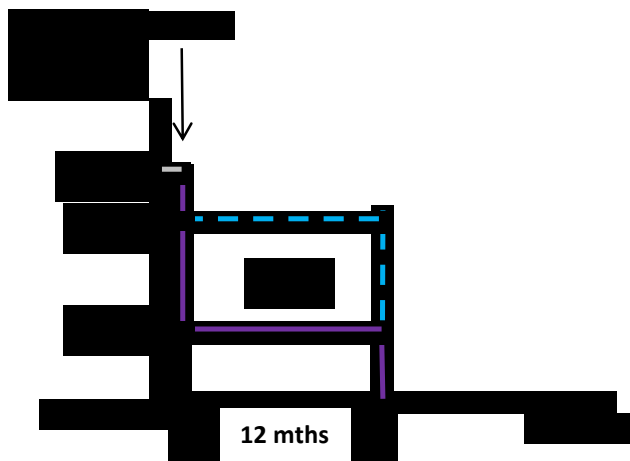


— Quality of life before being told about illness
— Current treatment
↓ Now (time of diagnosis)



--- Health Gain (HG) from new treatment

Scenario 1 (S1)



Text

Box 1

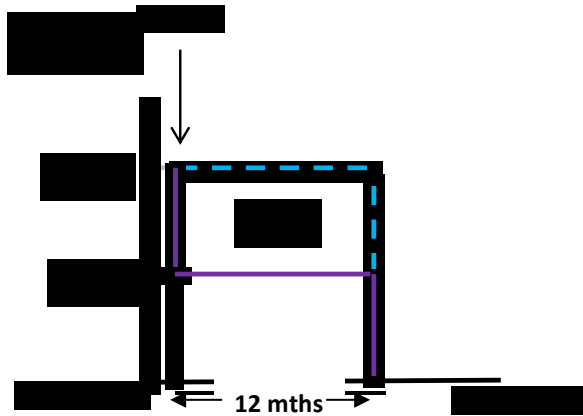
Patient X is diagnosed with a terminal illness. Doctors tell Patient X that with current treatment Patient X will live for 12 months in a quality of life of 30% before dying.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will improve Patient X's quality of life from 30% to 80% for 12 months.

Scenario 2 (S2)



Text

Box 1

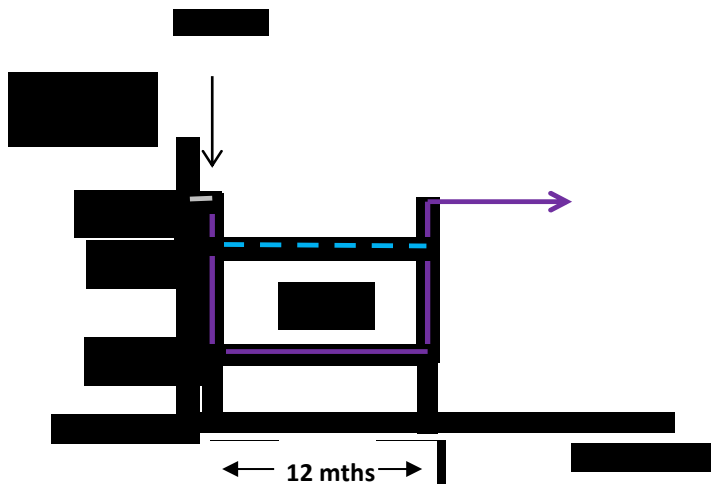
Patient X is diagnosed with a terminal illness. Doctors tell Patient X that with current treatment Patient X will live for 12 months in a quality of life of 50% before dying.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will improve Patient X's quality of life from 50% to 100% for 12 months.

Scenario 3 (S3)



Text

Box 1

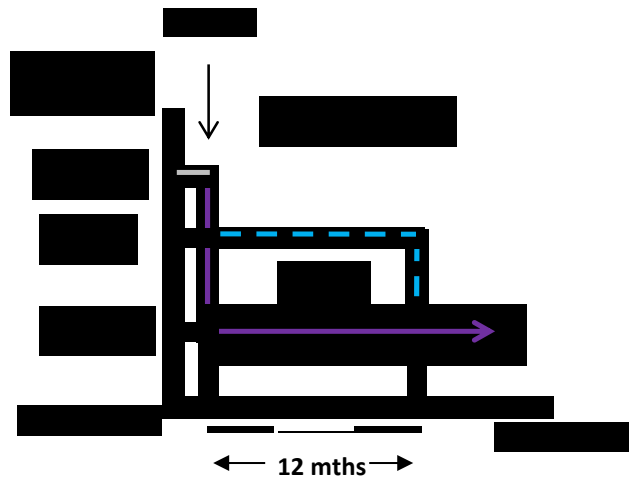
Patient X is diagnosed with a temporary illness. Doctors tell Patient X that with current treatment Patient X will have a quality of life of 30% for 12 months. After 12 months Patient X will return to full health.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will improve Patient X's quality of life from 30% to 80% for 12 months.
- After this year Patient X will return to full health.

Scenario 4 (S4)



Text

Box 1

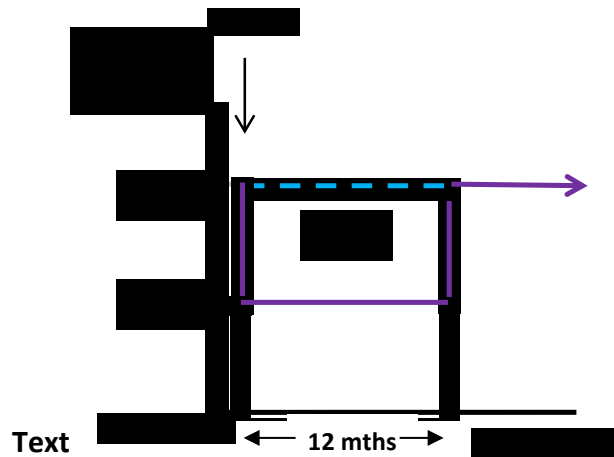
Patient X is diagnosed with a chronic illness. Doctors tell Patient X that with current treatment Patient X will have a quality of life of 30% for the foreseeable future.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will improve Patient X's quality of life from 30% to 80% for 12 months.
- After this year Patient X's quality of life will be 30% and remain at 30% for the

Scenario 5 (S5)



Box 1

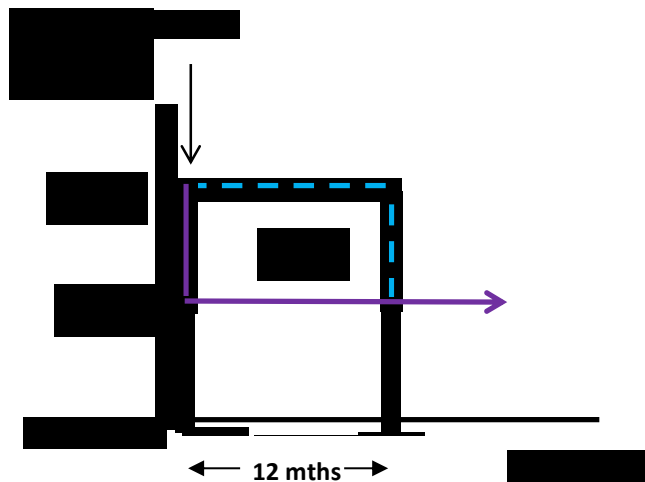
Patient X is diagnosed with a temporary illness. Doctors tell Patient X that with current treatment Patient X will have a quality of life of 50% for 12 months. After 12 months Patient X will return to full health.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will improve Patient X's quality of life from 50% to 100% for 12 months.

Scenario 6 (S6)



Text

Box 1

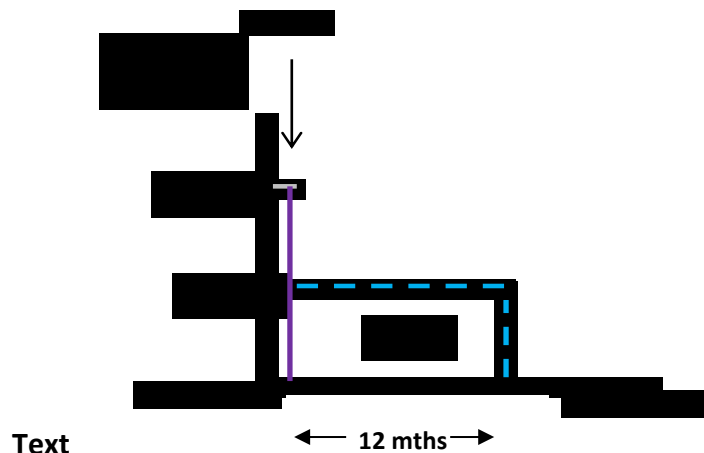
Patient X is diagnosed with a chronic illness. Doctors tell Patient X that with current treatment Patient X will have a quality of life of 50% for the foreseeable future.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will improve Patient X's quality of life from 50% to 100% for 12 months.
- After this year Patient X's quality of life will be 50% and remain at 50% for the

Scenario 7 (S7)



Box 1

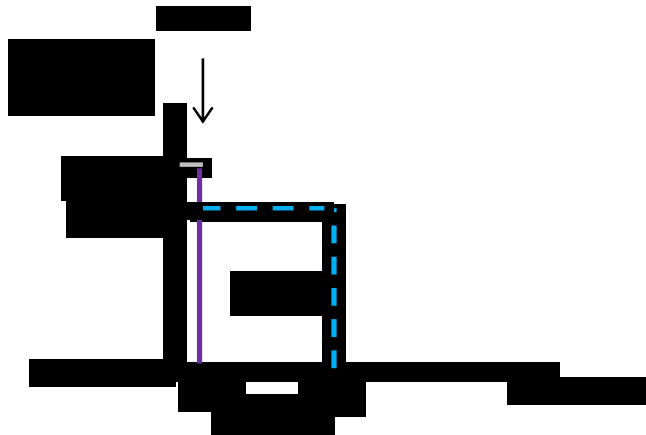
Patient X is diagnosed with a terminal illness. Doctors tell Patient X that with current treatment Patient X will live for another few weeks with Patient X's health getting worse before dying.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will extend Patient X's life by 12 months during which Patient X's quality of life will be 50%.

Scenario 8 (S8)



Text

Box 1

Patient X is diagnosed with a terminal illness. Doctors tell Patient X that with current treatment Patient X will live for another few weeks with Patient X's health getting worse before dying.

Box 2

The doctor tells Patient X that a new treatment has become available. This new treatment:

- Will extend Patient X's life by 7 months during which Patient X's quality of life will be 80%.

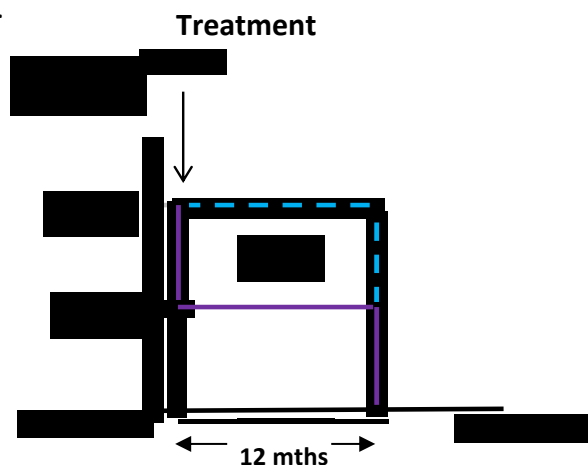
Appendix 2: PTO Example Question – Scenario 2 vs. Scenario 5

A version of this PTO question was programmed for the CAPI

****Red text shows programming notes****

Introduction

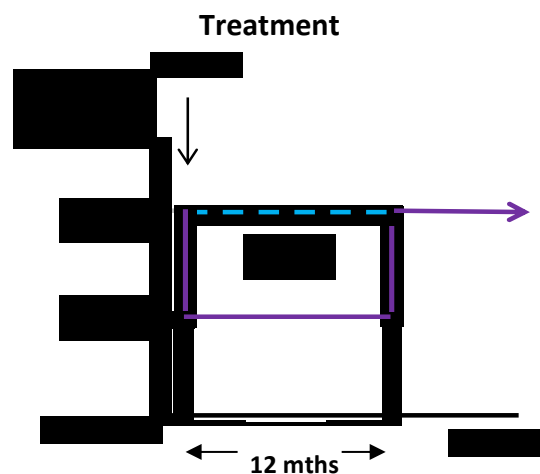
The NHS has a fixed, additional budget available to fund new treatments. Imagine that two new treatments – Treatment A and Treatment B – are available that cost the same amount of money. Only one treatment type can be provided (funding cannot be split between the two treatments). You will see questions that ask you to choose between providing Treatment A or Treatment B. Descriptions of the treatments follow.



Patients have been diagnosed with a terminal illness and are told that with current treatment they will live for 12 months in a quality of life of 50% before dying.

New Treatment A:

- Will improve their quality of life from 50% to 100% for 12 months.
- After this year they will still die.



Patients have been diagnosed with a temporary illness and are told that with current treatment they will have a quality of life of 50% for 12 months. After 12 months they will return to full

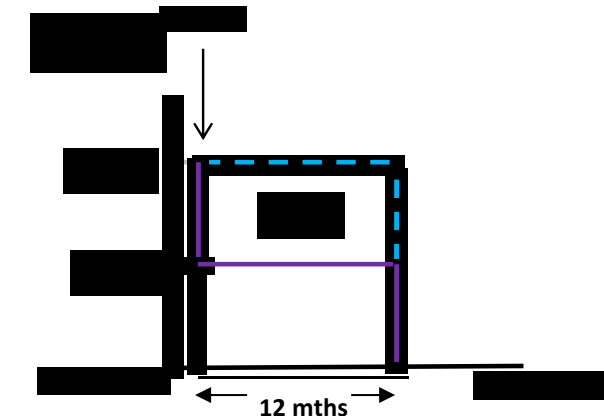
New Treatment B:

- Will improve their quality of life from 50% to 100% for 12 months.

Question 1

Imagine that, if funded, **Treatment A** can treat **100 patients** and **Treatment B** can treat **100 patients**.

Treatment



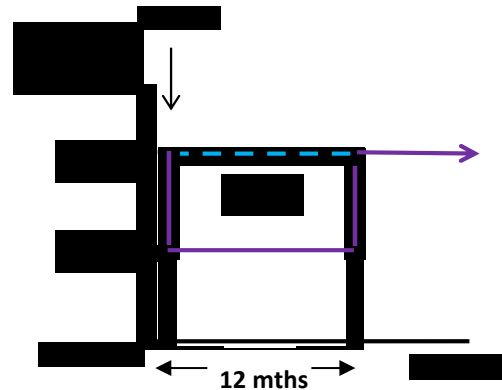
Patients have been diagnosed with a terminal illness and are told that with current treatment they will live for 12 months in a quality of life of 50% before dying.

New Treatment A:

- Will improve their quality of life from 50% to 100% for 12 months.
- After this year they will still die.

100 patients

Treatment



Patients have been diagnosed with a temporary illness and are told that with current treatment they will have a quality of life of 50% for 12 months. After 12 months they will return to full health.

New Treatment B:

- Will improve their quality of life from 50% to 100% for 12 months.
- After this year they will remain in full health.

100 patients

Which treatment should be provided?

Treatment

100



Treatment

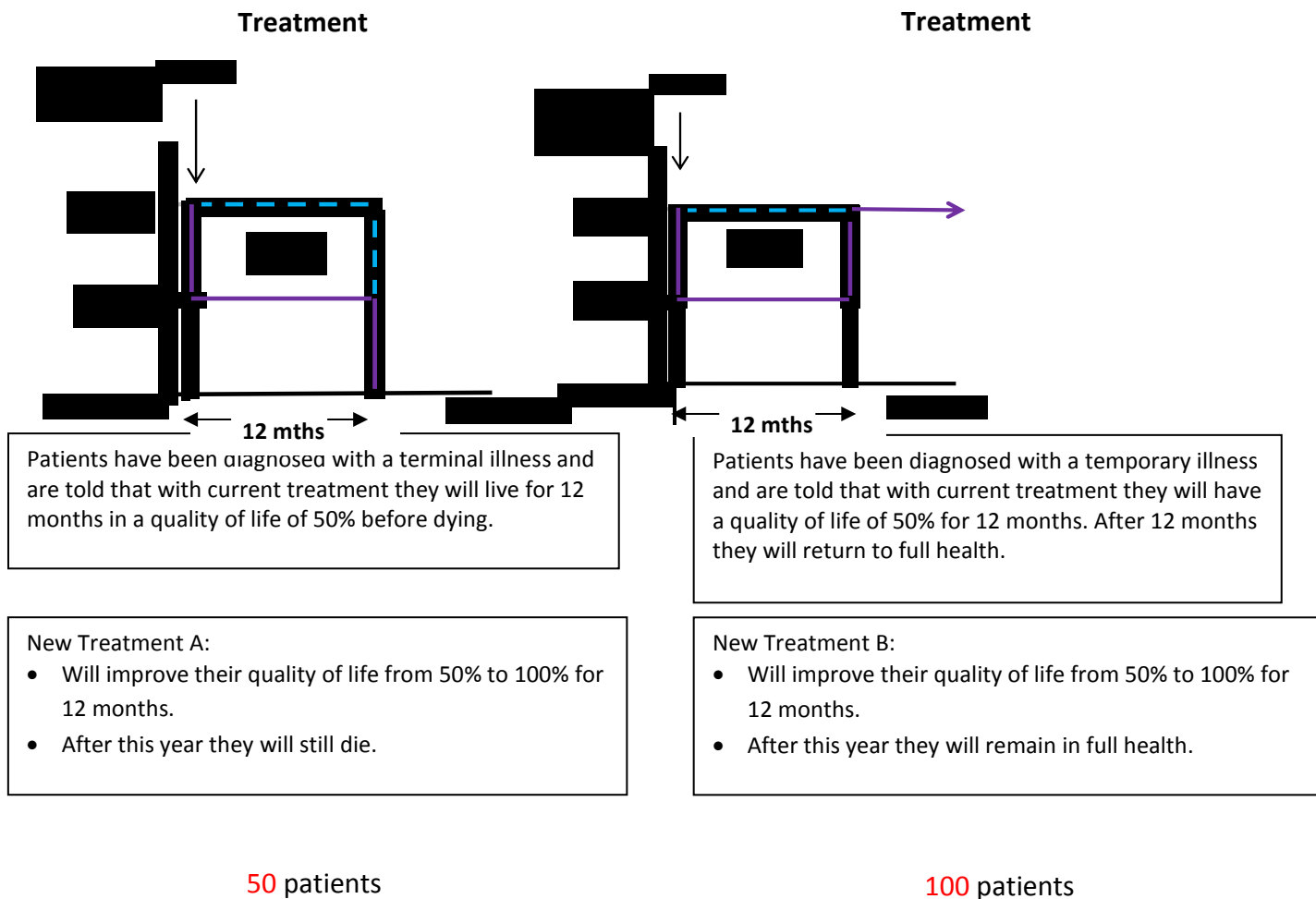
100



[Choice in Question 2 depends on answer to Question 1. In this example Treatment A is chosen.]

Question 2

Now imagine that, if funded, **Treatment A** can treat **50 patients** and **Treatment B** can treat **100 patients**.



Which treatment should be provided?

Treatment
50 patients



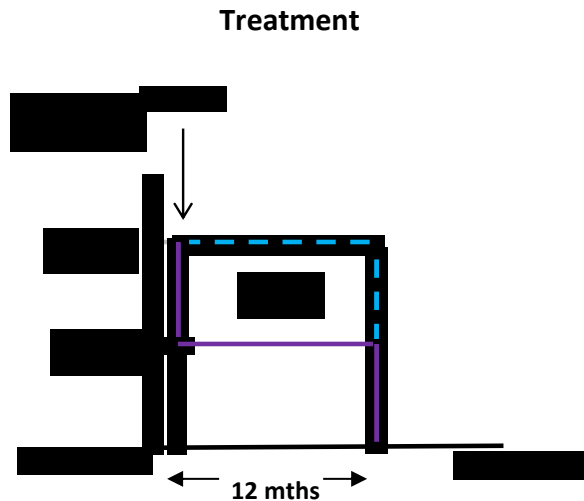
Treatment
100 patients



[Choice in Question 3 depends on answer to Question 2. In this example Treatment B is chosen.]

Question 3

Now imagine that, if funded, **Treatment A** can treat **75 patients** and **Treatment B** can treat **100 patients**.

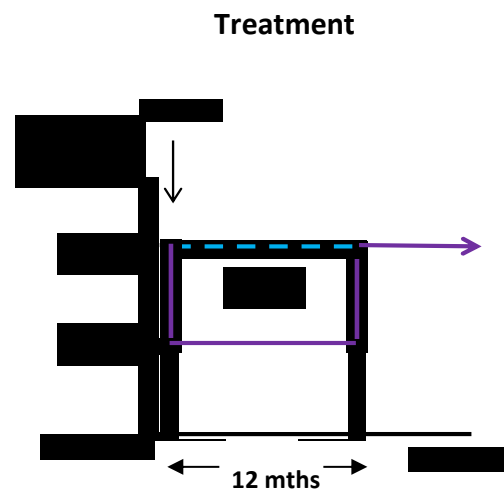


Patients have been diagnosed with a terminal illness and are told that with current treatment they will live for 12 months in a quality of life of 50% before dying.

New Treatment A:

- Will improve their quality of life from 50% to 100% for 12 months.
- After this year they will still die.

75 patients



Patients have been diagnosed with a temporary illness and are told that with current treatment they will have a quality of life of 50% for 12 months. After 12 months they will return to full health.

New Treatment B:

- Will improve their quality of life from 50% to 100% for 12 months.
- After this year they will remain in full health.

100 patients

Which treatment should be provided?

Treatment

75 patients

☐

Treatment

100 patients

☐

[Choice in Question 4 depends on answer to Question 3. Subsequent questions follow the same format until the point of indifference is reached.]

Appendix 3: Script for animation

Note on Appendix 3

- Voiceover to **stress** words in bold

1. The **National Health Service** is funded **directly** by the public.
2. The NHS **spends** its budget on **many** things, including doctors, nurses, beds, new drugs and treatments.
3. Although the health service budget is very **big**, it is still a **fixed** amount. There is **never** enough money to do **everything** we want.
4. Of course, the NHS budget could **grow** in the future.
5. But **this** research is about the money the health service has **now**, and the **best way** to spend it.
6. Because the budget is fixed, **difficult decisions** have to be made about **how** to spend NHS money.
7. When the NHS provides a service, the public **benefits**. But the public will **not** benefit if that service is **not** funded.
8. Because of this, and because the public **pays** for the NHS through its taxes, it is important that **decisions** on **how** to **spend** NHS money take into account the **views** of the public.
9. For example, thinking **generally** about **all** NHS patients, should we **concentrate** our funding on the treatment of people who are **most severely ill**? Or perhaps we should **focus** our spending on treatments that give people a **better quality of life**? Or should we **prioritise** the funding of treatments that help people to **live longer**?
10. These are **difficult** decisions to make, and there are **no** right or wrong answers.
11. As a member of the **public**, we need to know **your** views on this important topic.

Appendix 4: Example of PTO ratio calculations

Calculation of the 'ratio of means' involves assigning a value of 1 to the most-favoured treatment in each individual choice, with the less-favoured treatment receiving a value equal to the number of patients in the most-favoured group divided by the number of patients in the less-favoured group. Means across all respondents for each treatment (X and Y) are then calculated and then ratio of means determined. 'Median of ratios' comprises calculating ratios, X/Y (alternatively Y/X could be utilised), for each individual respondent and then taking the median of ratios across all respondents. These calculations are adapted from Pinto-Prades et al. (2014).

| Respondent ID | Raw responses* | | Ratio of Means (RoM) | | Median of ratios | |
|---------------|----------------|-----|----------------------|-----------|------------------|---------|
| | X | Y | | | X based | Y based |
| 1 | 25 | 100 | 1.00 | 0.25 | 0.25 | 4.00 |
| 2 | 10 | 100 | 1.00 | 0.10 | 0.10 | 10.00 |
| 3 | 5 | 100 | 1.00 | 0.05 | 0.05 | 20.00 |
| 4 | 100 | 5 | 0.05 | 1.00 | 20.00 | 0.05 |
| 5 | 100 | 10 | 0.10 | 1.00 | 10.00 | 0.10 |
| | | | Mean=0.63 | Mean=0.48 | | |
| | | | RoM (X/Y) | 1.31 | 0.25 | 4.00 |
| | | | RoM (Y/X) | 0.76 | | |

(*) Number (Ni) of patients X(Y) which are considered equivalent to 100 patients Y(X).